



Witness Name: **GRO-B**
 Statement No.: WITN0039-001
 Exhibits:
 Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 September 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I have been asked if I am legally represented and I can confirm that I am not.

I, **GRO-B** will say as follows: -

Introduction

1. My name is **GRO-B**. My date of birth and address are known to the Inquiry. I am a professional and work full time, I live with my partner of 28 years. For the purpose of the inquiry I am an affected person. I intend to speak about my Mum and our family. In particular, the nature of mum's illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.

How Infected

2. My mum, **GRO-B: M** was given a transfusion with contaminated blood and because of this she was infected with Hepatitis C. My Mum was infected with Hepatitis C, following a blood transfusion. She then suffered until she passed away on **GRO-B** 2017.
 - 2.1. My Mum was at Edgware General Hospital in 1976. She was there to have a hysterectomy, I think it was because she had been having a very bad time with heavy periods. She also had a blood transfusion around the same time. This was for loss of blood. I do not think any of us were given warnings about the blood, they just do it, even with my dad now. I do not remember seeing my mum with tubes and a bag attached to her, it was so long ago. But my Dad remembers this, so

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without a doubt she was given a blood transfusion. There was no advice given to Mum or Dad regarding the risk of infection from the transfusion.

- 2.2. For 9 years she had symptoms, she had time off work. She had tests done, but none of these tests came back saying she had Hepatitis C. I do not believe they did tests to check if she had Hepatitis C. She was getting looked at privately, at this time. My dad had got medical cover.
- 2.3. It wasn't until 1985, 9 years later, when Mum had a fall (we thought that she had a stroke). She was then sent to GRO-B hospital, where she had a number of tests and after this a consultant sat my Mum and Dad down and told them that my Mum had Hepatitis C.
- 2.4. They were told not to have any further physical contact, and not to have sex, they were told lots of things they could not do anymore. Nobody told us that it was through infected blood.
- 2.5. In 1991, at the Royal Free Hospital Mum and Dad were told by Mum's consultant that this was rubbish and that Hepatitis C was carried through the blood and not saliva, so they could have bodily contact. All that time they had been given wrong information. However, the damage had been done and they had no further bodily contact as they were too scared.

Other Infections

3. The only infection that mum had, was Hepatitis C as far as I know.

Consent

4. I am unsure if mum gave consent for any treatment or tests. She was never given any information that the blood she would receive could be contaminated or where it had come from.

Impact

5. My mum used to go out to dance's, she would go to the theatre. She used to come shopping with me all the time, every weekend. Once she was diagnosed with the infection she stopped doing everything she used to. She stopped going out altogether. She became very fragile and tired. She was always in her chair sleeping.
 - 5.1. Mum would not discuss the infection with me and my brother. She did tell us that she was always feeling ill. There never seemed to be a time when anything was ok. Whenever we visited we heard about her visits to consultants etc and I became even more frightened.

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- 5.2. There was a time that mum had to go to GRO-B at GRO-B hospital to help her with her mental health issues. Her anxiety and depression had become really bad. I remember mum getting angry, which was unlike her, she was usually supportive. I remember having an argument with her before I moved out of home, this was around 1978 when I was 24 years old. When I look back it was probably because she was scared and angry, perhaps a natural defence to what was happening to her.
- 5.3. These are the conditions my Mum had before she died.
- Liver disease Type B1
 - Sjogrens's syndrome
 - Type 2 diabetes
 - Hypertension
 - Fitted with a pacemaker
 - Previous thyrotoxicosis
 - Gastric issues
 - Chemosis
 - Loss of weight (2 stone)
- 5.4. My mum was treated in 1998 with interferon and tablets. The consultant came back from Chicago and started the treatment. She went into the Royal Free and was given injections everyday as well as taking the tablets. She was only treated for about 6 months and then they told her it didn't work, because she was too old for the treatment.
- 5.5. Mum was treated for her medical conditions which were as a result of her infection as follows: Hypertension – Atenolol, Perindopril, and Bendrofluazide. Sjogrens - eye drops, under rheumatology clinic at GRO-B Thyroid - levothyroxine. Chemosis – eye drops.
- 5.6. Looking back now, I regret not getting involved more. Mum and Dad were the type of people that would **always** do whatever they were told. They were not aware of any other treatments, the professionals guided them.
- 5.7. Mum told medical people that she was infected. She told the dentist and the dentist did not want to treat her. She did not receive dental care. When she died, she had hardly any teeth. She could only eat squashed up jacket potato.
- 5.8. The impact of my mum's infection has had on me and my family is immense. I completely freaked out when she was diagnosed. Mum told us she was going to die so it was as if we were waiting for her to die for a long time. It was almost as if I was preparing myself for her death for 40 years. Now I think her life could have carried on. The lack of communication about the disease affected our family in so many ways. I wouldn't have let her withdraw from life the way she did. No

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one ever told us. No knowledge of how bad this disease was. I was petrified to Google hepatitis C until after she died.

- 5.9. I was scared to go visit her. Every time I saw her, she would tell me that the consultant told me this, and that. I put more and more time between each of my visits to her. Fear was so ingrained in me. There were no groups I could talk to, that I had been told about – in fact we were never seen as a family considering both my brother and I were in our twenties. I was always petrified if she cut herself I didn't know what to do. My Brother has not been to Mum's graveyard yet, he really struggled with her death and still does.
- 5.10. My Dad cared for her for 40 years. This had a strong effect on him emotionally. When Mum stopped working, Dad had to get another job in the evenings. He worked all day and night. I think as a result of the care, time and effort in looking after my mum, **GRO-C**
- 5.11. My Dad remembers when medical professionals put my Mum in isolation (possibly at **GRO-B**). The Doctors were in protective clothing, Mum was so upset she signed herself out of **GRO-B**. I believe this led to Mum having a phobia of hospitals. She was embarrassed that she had Hepatitis C, to such an extent that, as mentioned, she did not leave the house and she has refused in patient treatment. Other people knowing and the embarrassment caused from this experience made her hugely anxious.
- 5.12. Dad was frightened from the minute the Doctors told them they couldn't touch. He didn't tell anyone about it. I think he was accepting that he would not be, going on holiday, not be going out, (Mum was almost phobic about it), I felt like he went with whatever Mum wanted.
- 5.13. We did not tell anyone about the Hepatitis C, even when she died. We never told anyone outside of the family. At the time, HIV was prevalent. I knew the panic in the public around this virus, we knew it was similar with Hepatitis C.
- 5.14. I have mentioned that because my Mum wasn't working, my Dad had to take further work on to bring money into the house.

Treatment/Care/Support

6. I do not remember my Mum and Dad ever being given support or counselling. I did not have that offered to me. Neither did my brother.

Financial Assistance

7. On 28 October 2005, Mum received the first payment of £20K from the Caxton/Skipton fund. Then in 2016, the Government announced a payment of £3500 per annum starting from 01 April 2016. This

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continued until she passed away. She received monthly payments of £252.50 from the Skipton fund.

- 7.1. Upon death funeral costs of £3500 were offered from the Caxton Foundation. My Dad gets winter fuel, this is approximately £519 per year, this is the deceased partner benefit.
- 7.2. To receive the £10K, the death certificate needed to say Mum died of Hepatitis C or at least a Doctor needed to say it was a *probable* cause of death. Mum's family Doctor wrote this, as Hepatitis C was missing from the death certificate, even though the hospital told us that after she had a bleed in hospital that they could not treat her as she had Hepatitis C. This amount was paid earlier this year.
- 7.3. I am unsure of what process Mum went through to get the £20K. The £3500 for funeral costs was processed after we, as a family informed the Skipton Fund, they said they would pay for the funeral, then Skipton liaised with the Funeral home directly.
- 7.4. To receive the £10K, I contacted the Skipton Fund, there was a long and complicated form to be filled out. It required evidence. I returned the completed form. The first time it was sent back was because the death certificate was supposed to state that Hepatitis C was the 'probable' cause of death and not a 'possible' cause of death, which it did on the first one I sent through.
- 7.5. I went to the Watford General where she died, to confirm it was Hepatitis C with a Doctor there. The hospital wouldn't confirm this so I had to go to Dr **GRO-B** at **GRO-B** Surgery, **GRO-B** **GRO-B**. This is the Doctor that my Mum was seeing for the past 10 years. I then sent the correct form back.
- 7.6. I didn't hear anything for weeks. I kept 'phoning, but there was no answer. Finally I got a hold of someone, who said Skipton Fund staff were only in one day a week. When I finally got through I was told that the letter was in the next batch going to EIBSS. This was at the end of October 2017. Then someone at the Skipton Fund couriered it to EIBSS. In March 2018, my Dad received £10K from EIBSS
- 7.7. With regards to the financial assistance that my Dad receives, I have more recently found out that he is entitled to £400+ per month in income top up , I only know this because I was searching through the England Infected Blood Support Scheme, (EIBSS) website and found this out by chance.
- 7.8. **GRO-C**
GRO-C We have been told that Dad has too much money coming in to receive funding. This is from his private pension, he receives £900 a month. We were told that the money

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coming in from Dad's pension is over the threshold (with no dependent children), this is difficult because **GRO-C** will cost £850 per month.

- 7.9. Overall, the forms are ok, but there is no way Dad could fill them out. All of the forms are on the computer and at the time both Mum and Dad had **GRO-C** so there is no way they could use a computer. Also, I am now aware that there are other grants, but at no time has anyone notified me of this more recent £400+ monthly grant.

Other Issues

8. There was a lack of information about everything, this highlights that we did not know where to turn when all of these things were happening to us. They must have a database of people. What about the people who don't know about these trusts?
- 8.1. Mum died at Watford General Hospital and the death certificate showed the cause of death:-

I (a) Hypovolemic shock,
I (b) Retroperitoneal (bleeding) haematoma.
II Type 2 Diabetes and multiple Comorbidities.
- 8.2. When Mum died we were not prepared for her death, by anyone, she was yellow and her mouth was wide open. I told the Funeral Home assistant that Mum had Hepatitis C, she didn't react, she was very nice about it. But we were told we only had 3 hours to view Mum's body. I thought this was strange. She said it was because of the Hepatitis C.
- 8.3. I have more recently found that the reason one must see the bodies quickly is because the undertakers can't do anything to them, so they have to act quickly. The undertakers are not allowed under their health and safety guidelines to embalm the body or even make the person more presentable.
- 8.4. It would have been helpful if there was someone there to explain what happens upon death, rather than experience it the way we did as it was extremely frightening.
- 8.5. I also wish that someone had told us that Hepatitis C is not a death sentence, because my Mum thought she had no time left to live.
- 8.6. I assumed that my Mum could die at any time.

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Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed

GRO-B

Dated

20/10/18